EVALUATION OF THE ICF/DD-CN PILOT PROJECT

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Purpose of the Study

The California Department of Health Services (DHS) was required by AB 359 to institute a waiver pilot program under the auspices of Section 1915(b) of the Federal Social Security Act. The purpose of the pilot program is to provide continuous, twenty-four hour skilled nursing care to medically fragile persons with developmental disabilities in waiver facilities—Intermediate Care Facility for Developmentally Disabled-Continuous Nursing (ICF/DD-CNs)—as a benefit of Medi-Cal. The goal of the pilot program is to explore licensure of a less restrictive health facility model for providing continuous skilled nursing for this population. Under previous models, these individuals either resided at home or in larger institutions providing twenty-four hour nursing care, such as skilled nursing facilities (SNFs), sub-acute facilities, acute care hospitals, or state-run developmental centers. In contrast, the ICF/DD-CN services are being provided in small, home-like, community-based residential settings.

The ICF/DD-CN is a new sub-group of facilities for persons with mental retardation as defined in federal regulations (42 CFR Section 435.1009) as facilities that:

1. Are primarily for the diagnosis, treatment, or rehabilitation of persons with mental retardation;
2. Provide, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration for health or rehabilitative services to help individuals function at their greatest ability.

Currently, there are two subgroups for ICF/DD programs in California: ICF/DD-H (Habilitative) and ICF/DD-N (Nursing), which provide consumers the opportunity to reside in 4-15 bed facilities within communities. Living in these facilities allows them to have more involvement with local communities and the opportunity to gain the skills to participate in community-based living at the highest degree possible.

DHS sought a federal waiver that would allow them to institute an ICF/DD-CN facility pilot program, thus enabling consumers who required twenty-four hour nursing care to

live in small, community-based residential settings. DHS proposed establishing ten pilot project facilities in California. They projected that sixty consumers would reside in these facilities. DHS anticipated that eighteen consumers would come from home where they would have been receiving sixteen hours of in-home LVN care each day. DHS projected that fifteen consumers would come from Developmental Centers, three from Distinct Part Nursing Facilities, three from Adult sub-acute facilities, twelve from Pediatric Sub-acute facilities, and nine from ICF/DD-CN facilities. Forty-five of the sixty consumers were anticipated to be non-ventilator dependent and fifteen were anticipated to be ventilator-dependent. DHS projected that the ICF/DD-CN pilot project would save $1,370,000.00 per year.

California Department of Health Services contracted with California State University, Sacramento (CSUS), Division of Nursing, to evaluate the ICF/DD-CN Pilot Project. This independent study was designed to evaluate the implementation of the pilot project. In addition, the evaluation was designed to assess the effect of the pilot program on the health, safety, and quality of life of the individuals residing in these facilities, as well as the cost effectiveness of this service model.

This study evaluates the implementation phase of the Pilot Projects with attention to the following:

1. Pilot facility selection process
2. Consumer Enrollment
3. Educational outreach
4. DHS assurance of provision of quality of care through monitoring activities
5. Providers' and consumers' satisfaction with the pilot process
6. Cost effectiveness of the ICF/DD-CN pilot program

Methodology

California Department of Health Services (DHS) made all records and documents associated with the ICF/DD-CN pilot project available for review by the CSUS evaluation team. Documents and records were reviewed to assess how DHS has

implemented the pilot project. Data were gathered on the pilot project facility selection process, educational outreach materials, monthly submissions from pilot facilities, reports of site visits and facility reviews, Treatment Authorization Requests (TARs), procedure manuals, special incident reports, and grievances.

Data were also gathered through interviews with key participants in the ICF/DD-CN pilot project. All facilities that had residents by January 1, 2003 were reviewed by CSUS research nurses. Residents and/or their guardians were interviewed by CSUS staff regarding their experiences with the pilot project. Providers (ICF/DD-CN facility managers and staff) were interviewed, focusing on their experiences with the consumers, DHS, Regional Centers, and the challenges of developing these new facilities. Records at the facilities were reviewed by CSUS research nurses. The nurses also assessed the facility environment, equipment and other resources. ICF/DD-CN staff was observed as they interacted with consumers. They were also interviewed about their experiences working with the ICF/DD-CN pilot project. Research nurses also observed consumers in day programs and school-based programs, and interviewed personnel at these sites. Findings of the research nurses were compared to findings of the DHS nursing staff (Licensing and Certification and Medi-Cal Operations Division). DHS personnel were interviewed about their experiences with the ICF/DD-CN pilot project and their perceptions of the strengths and weaknesses or the program. In addition, CSUS researchers discussed findings with DHS staff to clarify observations and ensure appropriate interpretation of findings.

Finally, focus groups were conducted with the Regional Centers referring and/or providing case management services for consumers residing in the pilot project facilities. Focus groups were conducted at the following Regional Centers:

- North Los Angeles County Regional Center
- Westside Regional Center
- Inland Regional Center
- Central Valley Regional Center
- Golden Gate Regional Center

- North Bay Regional Center

Overall, thirty Regional Center staff and consultants participated in the focus groups. Participants in the Regional Center focus groups had many years of experience as practitioners in their particular disciplines, with a range from 4.5 years to 42 years. In addition, their years of experience working with persons with developmental disabilities were extensive, with a range of 3 to 30 years, and an average of 15.4 years of experience. Most of these years were spent working for Regional Centers, which are the agencies in California responsible for providing case management, diagnoses (health and developmental), placement, evaluation of services, and consultation for persons with developmental disabilities. A number of disciplines were represented in the focus groups, including physicians (pediatricians, neurologists, and psychiatrists), nurses (BSN, PHN levels), social workers (BSW, MSW, and LCSW levels) administrators, quality assurance specialists, qualified mental retardation professionals (BA, MPA levels) community services coordinators (BA, MA levels) and case managers (BA levels).

Because of the small number of residents in the pilot project, qualitative methods of evaluation were used. The sample size was too small to support valid quantitative evaluation methods.

Results

The DHS proposal planned for ten pilot project facilities, with four to six residents residing in each facility, totaling forty to sixty residents. Although ten facilities were selected to be part of the pilot project, by January 31, 2003, there were seven pilot project facilities in the program with 23 residents in these facilities. Three facilities were no longer in the pilot, one was closed by DHS and two withdrew. Of the seven facilities, two ICF/DD-CNs were operating at full capacity (see Table 1). Three facilities had some residents, but were not full. Another facility had enrolled four residents, but did not have any residents by January 31, 2003: one resident was discharged soon after enrollment due to behavioral problems; two others were hospitalized and became ventilator dependent so

they could not return to the facility; and a fourth was hospitalized and then expired. (Investigation by L&C indicated that the facility was not at fault for this adverse outcome, but did recommend further investigation of the care provided by the acute care facility.) Soon after the data were gathered, one of the partially-filled facilities withdrew from the pilot project, and another one began to enroll residents.

The first residents enrolled in the pilot project were admitted in April, 2002. Two facilities were operational by June, 2002 (see Table 1). Two other facilities had enrolled consumers by the end of September, 2002, but were not filled to capacity by the end of the data gathering period. The fifth and six facilities were operational by November, 2002 and January, 2003, respectively.

As can be noted on Table 1, the majority of persons enrolled in pilot project facilities resided in ICF/DD-N facilities prior to placement in the ICF/CC-CN facilities. DHS had projected that 15% of the pilot project residents would be from ICF/DD-Ns, with 55% coming from either their own homes (30%) or from DCs (25%). Instead, 60% (n=15) of the residents came from ICF/DD-N facilities, 16% (n=4) from DCs, and no residents came from their own homes. The remainder came from Sub-acute, SNF, and acute care facilities.

Table 1: Facilities Studied by Consumer's Prior Residence and Ventilator/Non-Ventilator Status

ICF/DD-CN Facility	Began Admissions	Number of Clients	Residence Prior to ICF/DD-CN Pilot Project Facility					Use of Ventilator	
			ICF/DD-N	SNF	Sub-Acute Adult	DC	Acute Care	Vent	Non-Vent
1	04/03/02	6	5				1	5	1
2	06/01/02	6	6						6
3	08/05/02	4		2	2			2	2
4*	09/23/02	2				2			2
5	11/07/02	3	2		1			1	2
6	01/27/03	4	3		1			2	2
7	> 01/30/03	0							
Total		25	16	2	4	2	1	10	15

* One resident expired in December, 2003, another was hospitalized in November, 2003, and did not return to the ICF/DD-CN, and a third, not counted on this list, was hospitalized 3 weeks after admission and did not return to the facility. The agency was not at fault for these adverse outcomes, based on reviews by L&C.

Pilot Facility Selection Process

DHS Selection Protocol

DHS described the plan for reviewing facility applications in the waiver document submitted to US Department of Health and Human Services. This process was further delineated in the June 19, 2001, correspondence from Gail Margolis, Deputy Director, Medical Care Services, DHS, to Ms. Linda Minamoto, Associate Regional Administrator, Division of Medicaid-Region IX, U.S. Department of Health and Human Services, Health Care Financing Administration, San Francisco. According to the documents submitted, those who wished to become ICF/DD-CN providers had to submit an application form that included documentation delineating the following:

- Agreement to accept only waiver eligible Medi-Cal beneficiaries; to meet beneficiaries' health care and developmental needs; to follow all state and federal laws and regulations; to provide data and information required by DHS for evaluation of the pilot projects.
- Ability to meet all waiver requirements for participation, including licensure as an ICF/DD-N or eligibility for licensure as an ICF/DD-N facility; a licensing history that indicates compliance with state and federal licensing and certification requirements during the three years prior to completing an application.

In addition, providers had to demonstrate, as determined by a Licensing and Certification (L&C) survey, compliance with regulatory requirements for the general physical plant, staffing, and equipment and supplies.

In order to screen the provider applications, DHS developed an ICF/DD-CN Pilot Program Facility Application Rating Form. Facilities were screened using a numeric scoring process. Areas addressed in the application scoring form were the following:

1. Sample staffing pattern, based on the facility's license capacity, for one week (10/145 points; 6.9%).
2. A profile of projected consumer needs that addressed their acuity level and medical needs as follows:

- Acuity level/medical needs: target population defined (homogeneity); predictable and unpredictable needs were anticipated; MD orders and support for twenty-four hour needs were obtained; medical plans of care support the need for continuous nursing (40\145 points; 27.6%).
- Nursing service needs: licensed nurse competencies parallel anticipated acuity needs of consumers; identification of potential placement sources (agencies, facilities); identification of appropriate twenty-four-hour community resources for the target population (30/145 points; 20.7%).

3. Profile of projected program is appropriate for:
    - Projected Medical needs; projected age range; self-determination needs discussed (as appropriate); and, at appropriate frequency for activity programs, training/education programs, and sensory stimulation programs (30/145 points; 20.7%).
    - Consumer placement in programs (10/45 points; 6.9%)
    - Auxiliary power (generator) (10/145 points; 6.9%)
    - 4-6 bed facility (10/145 points; 6.9%)
    - Complete and accurate criminal clearance submission (5/145 points; 3.4%).

Each application was scored individually by 3 different DHS employees, one representing Medi-Cal Policy Division, one representing Medical Operations Division (MCOD), and one representing Licensing and Certification (L&C). Their scores were then collated, and a final score, consisting of the sum of the three reviewers' individual scores, was calculated. Additional scores, based on a letter of support from a Regional Center and compliance with state and federal regulations for 3 years, could be used to break ties (there weren't any). A committee, consisting of the following representatives, reviewed the scoring and ranked the facilities:

- DHS: Fourteen DHS staff, representing Medi-Cal Policy Division (MCPD), Medi-Cal Operations Division (MCOD), and Licensing and Certification (L&C).
- Regional Center : Two nurses represented the Regional Centers

The committee's choices were reviewed and approved by Department of Health Services (DHS) management.

All facilities originally selected for the pilot project were 4-6 bed facilities. Due to the withdrawal of one applicant, an alternative 12-bed facility was selected to be part of the pilot project. The review process was objective and based upon factual evidence of ability to provide care that met with state and federal regulations.

Follow-up by L&C was clearly documented in department records. Pilot facilities provided documentation of review and approval of their facilities by state fire marshals. In addition, L&C staff conducted scheduled on-site reviews that addressed the physical plant, staffing, equipment, and supplies as described in the waiver document. In addition, L&C noted whether criminal record clearance requirements were met, as specified in the Health and Safety Code (1265.5, subdivision a). Any deficiencies were discussed with the providers and then documented in follow-up letters, usually sent within a few days of the site visits. In one case, a facility did not pass initial licensure because it was not able to obtain a fire marshal's clearance due to many problems including unsafe walkways, a lack of ramps, exposed pipes, missing closet doors, missing screens, chipped kitchen counter, limited hot water flow, inadequate eating and cooking equipment, and so forth. The facility also did not have a proper generator. The operators of this facility decided to withdraw from the pilot project rather than to make the required revisions. Another facility was noted to be non-compliant with nursing services, medical records, and drug regime requirements. The facility was re-assessed 34 days later and found to be in compliance in these areas: staff changes had been made, a clean/dirty utility area was established, and the facility had implemented their policies for equipment maintenance and cleaning. There was evidence of frequent interaction and guidance from L&C during this initial review process.

For the most part, the Regional Center staff who participated in the focus groups with CSUS felt that DHS selected pilot projects with excellent reputations. However, the staff from some Regional Centers indicated that they were not involved in the pilot facility selection process. They believe that their feedback could be very useful to the state. They

know the facility providers in their areas very well, and know which providers consistently provide care of a high quality. They have found that facilities with a long and successful track record of running programs for those with disabilities provide the best care for the ICFDD-CN population. Regional Center staff indicated that it is essential that the facilities have good communication with other agencies, that they have a history of effectively caring for persons with disabilities, and that the types of sub-specialists needed by persons who would reside in ICF/DD-CN facilities are available and willing to accept them into their practice. In some areas, for example, neurologists will not accept anyone with Medi-Cal, in other areas neurologists are available for children, but not for adults with disabilities. They indicated that it is essential that pilot facilities be located near hospitals with the types of sub-specialists who are needed to treat the ICF/DD-CN consumers. The Regional Center physicians stated that they know who the local Medi-Cal providers are, and can evaluate whether those in the area of a potential facility will be able and willing to provide the quality of medical care and the depth of services needed by the medically vulnerable individuals served in ICF/DD-CN pilot projects. The Regional Centers indicated that they have local insight and expertise that could be of value to DHS in the facility selection process.

Recommendations

In their response to the US Department of Health and Human Services request for clarification of several items of the waiver document DHS indicated that the Regional Centers would be responsible for "referral of appropriate consumers to the ICF/DD-CN facilities…" (p. 4, June 19, 2001, letter to Linda Minamoto, Associate Regional Administrator, Division of Medicaid-Region IS, US Department of Health and Human Services, San Francisco). Since the Regional Centers must play a significant role in the implementation and monitoring of the ICF/DD-CN pilot project facilities, it is important to get their input and buy-in on this project. Many Regional Center staff expressed interest in helping the state select pilot facilities. It is advisable that DHS include representatives from those Regional Centers providing services to ICF/DD-CN facilities in the selection of new facilities. Feedback should be sought from Regional Center staff involved in resource development as well as from members of the clinical teams. If

Regional Centers believe that a proposed facility is not viable or appropriate, then the facility should not be included in the ICF/DD-CN Pilot Project.

DHS' Strategies to Confirm Competencies of the Pilot Facility Staff

DHS monitors pilot facility staff competencies in a number of ways. New facilities must submit a program plan to the California Department of Developmental Services (DDS) that contains the following elements:

- Number of eligible consumers
- Profile of the consumer population using the Client Development Evaluation Report (CDER) supplied by DDS
- Summary of consumers' needs
- Description of the program elements as specified in Title 22
- A week's program schedule for consumers
- Facility staffing patterns, an organizational chart, and members of the interdisciplinary team indicating their discipline and hours per week
- Description of the space for program elements
- Description of available equipment
- 12 months of in-service plans, topics as listed in Title 22
- Plan for utilization of community services
- Provisions for assessing each consumer, using standardized forms furnished by DDS; individualized service plans developed by the interdisciplinary team under the direction of a QMRP
- Plan for a behavior modification program, if used, as defined in Title 22
- Training program for drug administration by unlicensed personnel in accordance to Title 22 requirements
- Any changes in the facility operation shall be reported to DDS within 10 working days

DDS provides guidance to facilities on completion of the plan, if requested. The Program Plan is used to ensure providers have a basic understanding of how to meet the needs of persons with disabilities in a safe and organized environment.

After DDS reviews and approves the plan, DHS is notified. L&C makes initial sight visits to ensure the agency in compliant with federal and state regulations. MCOD works with the facilities, Regional Centers, and other agencies to identify consumers appropriate for placement n the ICF/DD-CN facilities. Based on reviews of consumers' clinical needs, MCOD will approve a treatment authorization for consumers to reside in ICF/DD-CN facilities. Both L&C and MCOD began making monitoring visits soon after residents were placed in pilot project facilities, always within a few days or a few weeks.

DHS maintains strict monitoring of facility staffs' ability to provide services on a regular basis. All clearances, including criminal and licensing clearances, are reviewed by DHS and confirmed on each quarterly review by L&C. All facilities submit documentation of their in-services. Staff attendance is monitored by L&C during site visits. For example, one facility was told to maintain records for all staff, licensed and non-licensed, including administration staff, for the basic attendant training, specialized procedure training and competency. The facility was informed that this would be identified as a deficient practice if it was not complete by the next visit.

When a facility desires to certify staff for specialized procedures they must submit their education plan, protocol, and method of evaluation to DDS. There it is reviewed, and either approved, approved with modifications, or returned to the facility for changes and re-submission. The DDS reviewer also supplies facilities with additional fact sheets, such as what to look for as signs and symptoms of adverse reactions to a procedure. During site visits, L&C and MCOD observe staff as they perform approved special procedures to confirm their expertise. If problems are noted they inform the agency. For example, in one case L&C staff noted that the agency staff did not check for GT placement before initiating a feeding, and the facility was informed that this was not an acceptable practice. During site visits L&C staffs also monitor re-certification of ICF/DD-CN staff for approved special procedures. DHS records clearly document actions to remediate any identified problems. For example, the RN consultant in one ICF/DD-CN did not realize, until advised by L&C staff, that once an attendant is

approved to perform a specialized procedure he/she must be observed and recertified every 3 months.

L&C and MCOD nurses communicate regularly with one another. MCOD notes any problem areas and reports these to L&C who ultimately have the responsibility for notifying agencies of any concerns. L&C and MCOD make quarterly sight visits to facilities. L&C nursing staff reviews charts, in-service schedules, specialized procedure training and certification, and care plans to ensure that facility staff stay within their scopes of practice. L&C nursing staff sought clarification from the Board of Nursing regarding procedures and functions that may be performed by registered nurses (RNs), and those that can be performed by licensed vocational nurses (LVNs). In addition, L&C produced a document that clearly describes the role of the RN in an ICF/DD-CN, as defined by regulation. This document stipulates an RN's responsibilities for the provision of nursing services, coverage of health care information, teaching, physical exams, nursing services, and attendant training. Roles of all professionals are routinely reviewed by L&C. In one case a facility was closed, in part, because the staff carried out functions that were outside of the scopes of their practice. In addition, further investigation demonstrated that one individual was not currently licensed in a specialty he indicated he was licensed in. This case was thoroughly investigated by the nurses working in L&C and MCOD; response to findings was immediate and comprehensive.

The Regional Centers indicated that the residents of the ICF/DD-CN pilot project facilities are very medically fragile. Careful and ongoing oversight of staffs' ability to care for this vulnerable population is needed to ensure the safety of the residents. Regional Center employees indicated that it is important that DHS have close communication with Regional Center staff regarding any concerns about facility staff competencies. The Regional Center employees, including case managers, QMRPs, quality assurance personnel, nurses and physicians, indicated a desire to work collaboratively with DHS. Most of the Regional Centers offered to help monitor key competencies and also provide technical assistance to agencies to enhance ICF/DD-CN

staff skills. Regional Center staff also offered to help reinforce recommendations made by DHS.

A review of DHS records supports the need for ongoing assessment of ICF/DD-CN staff's competencies, since facilities continue to need guidance and oversight regarding staff practice. In one facility, for example, DHS staff had concerns regarding consumers having recurrent respiratory infections. During a recent site visit the DHS representatives noted staff did not follow appropriate procedures for hand washing and suctioning. These basic competencies can significantly influence consumers' health outcomes.

In addition, both record reviews and interviews indicate that facilities seek guidance and support for ensuring their competence from DHS nurses. Although not a traditional part of their role, the L&C and MCOD staff has responded to ICF/DD-CN facilities desire for technical assistance. DHS recently (March 5, 2003) provided a day-long training program that covered several topics related to staff competency including the following topics:

- Waiver Requirements: ICF/DD-CN Facility
- Condition of Participation: Health Care Services (listing relevant federal regulations)
- Required Documentation for TAR Adjudication/Authorization of Service for ICF/DD-CN Pilot Waiver
- DS CAST: Index to Federal Regulations (CFR)
- Conditions of Participation Compliance Guide
- Relationships and Responsibility: Federal Regulations and Interpretive Guidelines
- Active Treatment Program
- Human Rights Committee
- Tools for Success (a guide for reviewing consumer's records for adherence to federal regulations and the Individual Program Plan)
- Memo on Attendant Training Program-Specialized Procedures describing regulations, and roles and responsibilities
- Services Provided Under Agreement With "Outside Resources"
- Individual Program Plan (Federal Regulations)

- Physician Services
- ICF/DD-CN Facility Reporting to Licensing and Certification
- Survey Time (advising on what to expect from a DHS survey site visit)
- The Medication Pass (description of the DHS observation of the distribution of medication(s) to consumers)
- Medi-Cal Operations Division (MCOD) (a description of their roles and responsibilities)
- The Roles of the Registered Nurse
- The Role of the QMRP
- Injury Reports
- The Investigation of an Unusual Incident
- Choices: Federal Regulation W-247

Feedback from agencies participating in the pilot project has been that this information is excellent, and would have helped agencies to be more successful earlier in the pilot project had it been available at the beginning. The positive impact of the DHS nurses' efforts is evident. CSUS nurses have noted improvements, for example, in the methods ICF/DD-CN staff use to document care and organize records.

Recommendations

DHS nursing staffs' efforts to provide technical support regarding key aspects of care, such as how to develop an effective care plan and guidelines for caring for those with gastrostomy tubes, is to be commended. This type of technical assistance is needed to ensure the success of the ICF/DD-CN pilot project. The provision of technical assistance is often a part of the implementation of new projects, although traditionally these services are provided by a contractor. The DHS nursing staff is capable of offering technical assistance and their statewide point-of-view, as well as their in-depth insight into each facility's strengths and weaknesses, gives them a unique perspective of areas of practice that need to be addressed. The following activities could strengthen technical support activities:

- A needs assessment of ICF/DD-CN facilities to identify areas in which they would like more assistance.

- Closer liaison with Regional Centers on a local basis to coordinate oversight and the provision of technical support.
- DHS be staffed to reflect additional responsibilities related to technical assistance.

Currently, both MCOD and L&C are having more frequent contact with pilot project facilities than generally provided by these two agencies. In view of the fact that this is a pilot project serving medically fragile individuals this level of oversight is needed until there is stabilization of the ICF/DD-CN facilities and more is known about the ability of the project facilities to provide the level of care needed by their residents. Many areas addressed by DHS nurses during the implementation phase of the pilot project are basic aspects of care. Hand washing, for example, is a very basic part of the provision of safe health care and important for the prevention of the spread of infection. The pilot project offers DHS the opportunity to assess the level of oversight and training facilities will need to ensure they provide safe residential care. It may be that a higher level of oversight will be needed for all new ICF/DD-CN facilities until they develop more expertise in the care and management of the health needs of medically fragile persons in a home-like setting.

Access of Pilot Projects to Emergency Room Services, Acute Care Hospital Facilities, Medical Care and Sub-Specialty Care, and Ancillary Care Services

All pilot facilities are within ten minutes or less from emergency rooms and acute care hospital facilities, and have made local fire departments aware of their residences. Regional Center staff expressed concern that acute care hospitals may not have the expertise to address the ICF/DD-CN consumers' special needs. The Regional Centers have found that acute care staff request nasogastric or gastrostomy tube placements because they are not comfortable feeding consumers by mouth. One Regional Center has implemented a policy to not authorize emergency gastrostomy tube (G-tube) placements when requested to do so, because of the misuse of this procedure by acute care hospitals. The Regional Center staffs suggest that hospitalized ICF/DD-CN consumers may need one-on-one care from pilot facility staff, especially if the consumers are non-verbal. One ICF/DD-CN resident, for example, was transferred from one acute care facility to another acute facility and the physician orders regarding his/her special diet were not included in

the transfer data. Several days later the ICF/DD-CN nurse brought this error to the attention of the acute care nursing staff. The Regional Centers propose that funds should be available that will enable a staff person to be with consumers when they are hospitalized in acute care to ensure that their care is safe. Currently, some developmental centers (DCs) make this type of arrangement when their residents are hospitalized in acute care facilities.

Primary care physicians review consumers' health status at least every 60 days, as documented in consumer records. Each facility had agreements with a number of sub-specialists, generally including neurologists, gastroenterologists, podiatrists, psychiatrists, and pulmonologists. Several facilities had problems accessing one or more sub-specialists. One, for example, had problems with accessing neurology and ear, nose and throat specialists, whereas another had problems accessing a pulmonologist. Those sub-specialists who were readily available could generally schedule an appointment within 2 weeks. Those who were not as readily available were not able to schedule appointments for up to 4 months; although there was access to their services, it was delayed for some sub-specialties in some areas. Regional Center physicians indicated that they know if sub-specialists are available in their regions who will provide services to those on Medi-Cal. Therefore, the Regional Centers could assist DHS in screening facilities because they would know if sub-specialists would be available to meet the needs of an ICF/DD-CN applicant's proposed type of resident. If, for example, neurologists are not available, then a facility desiring to care for those with seizure disorders would not be funded. An alternative would be to utilize tele-medicine for provision of sub-specialty services that are not available locally. Another alternative is to provide special clinics for consumers, transporting a team of specialists into underserved areas.

There is evidence in records that consumers have access to ancillary care providers, and ICF/DD-CN staff indicated there were no barriers to accessing ancillary care. Nutritionists, physical therapists and occupational therapists are the most frequently utilized type of ancillary care provider. They function as part of an interdisciplinary team and there is evidence of their participation in care planning. DHS staffs monitor

compliance with these plans. Variations from the plan are noted and presented to the facility staff. One consumer's special diet, for example, was not followed in the day program. DHS recommended the facility develop a plan to improve communication with the day program, including documentation of the consumer's adherence to the diet. The facility also needed to educate the day program staff regarding the consumer's health, and develop a written agreement with the day program regarding their roles and responsibilities for addressing the consumer's special health needs.

Recommendations

Acute care facilities may not offer the specialized nursing care needed by ICF/DD-CN consumers. In the event that consumers are hospitalized the ICF/DD-CN facility nurses need to be available to ensure safe care of consumers. Consideration should be given to the Regional Center's suggestion of providing special funds to cover the additional nursing hours so that ICF/DD-CN RNs can stay with consumers when they are hospitalized.

The Regional Center physicians have linkages to local Medical communities that give them expertise in the availability of physician services, including sub-specialty services, for consumers with developmental disabilities. Prior to funding an ICF/DD-CN facility DHS should contact the local Regional Centers' medical staff to confirm access to the types of medical care needed by the population to be served. If sub-specialty care is not available then consideration should be given to supporting efforts to provide these services through tele-medicine or specialty clinics.

Consumer Enrollment

The greatest challenge to implementation of the ICF/DD-CN pilot project has been the lack of consumer enrollment. There have been three significant barriers to enrollment: first, the possible "sun setting" of the legislation that initiated the pilot project; second, changes in the California economy; third, delays in the identification and enrollment of consumers. Legislation to extend the ICF/DD-CN project was needed to extend funding

for the pilot projects beyond 2002. This legislation was not passed until September 30, 2002. Families and Regional Center staff were concerned that the pilot project would not be extended. When consumers with developmental disabilities are transferred from one facility to another there is increased risk to their health and welfare from "transfer trauma." This is particularly true for more vulnerable individuals, especially those who are medically fragile. Therefore, there was concern about transferring when the pilot project might end within a short time period. This situation was somewhat alleviated by extension of the ICF/DD-CN pilot project until 2006. However, the recent downturn in California's economy, combined with the significant decrease in the state's budget, has caused some anxiety about the sustainability of the ICF/DD-CN pilot project.

Regional Center personnel indicated that ICFDD-CNs provide an alternative to living in more restrictive environments for those who need continuous nursing services. They are viewed as a much needed service, since the alternatives lack the home-like atmosphere and personal attention of the ICF/DD-CN facilities. SNFs, in particular, were seen as negative environments for their consumers. Regional Center staff indicated that SNF personnel often do not know how to interact with Regional Center clients, who deteriorate emotionally and psychologically in these settings. Regional Center staff consistently stated that SNFs do not provide programs for consumers with developmental disabilities, and staff is often not interested in adding to their work load and, therefore, avoid taking on additional tasks designed to meet the needs of consumers with disabilities. Regional Center staff indicated that sub-acute facilities, another alternative, do not provide a personal environment for consumers. They are moved around, predictably not keeping their same room. In addition, Regional Center staff stated that consumer's personal material goods tend to disappear in both types of settings.

In contrast, Regional Centers indicated that there is much more personal and positive interaction between staff and consumers in these small facilities. The Regional Center personnel were very impressed with the staff at the ICF/DD-CNs. They felt that they provided a nurturing and respectful environment. For example, ICF/DD-CN staff explains to clients why they are taking their medications and what they do for them.

Regional Center employees indicated that the ICF/DD-CN staff are sensitive to the needs of persons with disabilities, are very committed to the population, and are familiar with their unique needs. Relationships between staff and consumers are more personal and more intimate than those in larger institutions. Even those who are very disabled—lack self-care and are profoundly retarded—seem to respond positively to the ICF/DD-CN staff. A common theme was reflected in the following statement, "It is as though they react to their sense of commitment to the consumers. The staff has an emotional attachment to the clients who seem to sense this caring. This is particularly meaningful to those who have previously had bad experiences with care providers."

Although there has been some wariness about the ICF/DD-CN program because of concerns about their ability to meet consumers' medical care needs, many Regional Center staff now hope that all consumers who are medically fragile could reside in ICF/DD-CN facilities. The facilities have protocols for safety & health, nutrition, and goals for the consumers. Regional Centers indicate that the atmosphere in the ICF/DD-CNs is very positive and not stigmatizing. The staff are excellent, encourage consumers to be adventurous, establish personal goals (as age appropriate), and encourage them to try different activities. There is a good match among the residents, with most about the same age and at the same developmental level. As one Regional Center employee stated, "In the ICFDD-CN consumers are valued for their individuality, they are allowed to express themselves, and they feel like they live in a home." Regional Center staff expressed anxiety about the impact on consumers who come to think of a residence as their home, and then must move back to a more restrictive, less personal environment if this program ends.

The Regional Centers have encountered resistance to placement of individuals with developmental disabilities in ICF/DD-CNs from some parents for the following reasons:

- A fear that a "pilot project" is temporary; family members will not be able to go back in to the DC setting at the end of the pilot and alternatives are worrisome to many parents.

- Some families feel there is greater risk of closure with small, individual facilities; then they will need to find alternative placements for their member with developmental disabilities.
- Parents, in particular, are apprehensive about having their child displaced due to facility instability.
- Some parents are more comfortable with large facilities, believing they have better equipment and more access to health care services.
- Parents have heard horror stories about treatment in community-based facilities and are adamant about maintaining DC placements.

Conversely, the Regional Centers find that families with members enrolled in an ICF/DD-CN are very happy with the care provided in this setting. Parents like having their children closer to them. They also like the fact that those caring for them are loving and genuinely affectionate, as well as highly skilled. Some families have noted that their child, for example, feels comfortable and happy with their new caregiver. In addition, the families find that the nurses are able to keep their children healthier than they were at home.

Some Regional Centers suggest that guidelines for placement be further refined. As the Regional Centers have been able to recruit persons to be enrolled in facilities they have encountered some problems. The regional centers have found that those who are medically fragile and unstable are much more likely to end up repeatedly hospitalized. This puts the individual as well as the ICF/DD-CN facility at risk. The person who is hospitalized is at increased risk for adverse outcomes while in an acute facility being cared for by nurses who may not be skilled in the delivery of services to individuals with developmental disabilities. The ICF/DD-CN facility may face financial risks if the person is hospitalized for any length of time, because they will lose one sixth of their income. Consequently, they may not be able to sustain a bed until the person returns from acute care. Regional Center physicians indicate that there is a significant difference between stable and fragile and unstable and fragile consumers. Those who have multiple, serious health problems that are stable can easily adapt to a less restrictive environment, like an ICF/DD-CN. Those who have health problems that are unstable-- subject to frequent

onset of acute illness or rapidly deteriorating health conditions-- on the other hand, may not fare as well in a less restrictive environment. They are more likely to need to be hospitalized on a regular basis, thus increasing their personal risk and the provider's financial risk.

The Regional Center staff expressed some confusion about which consumers facilities will accept. One Regional Center indicated that an ICF/DD-CN facility turned down 18 referrals, including many from DCs, which was frustrating to the referring employees. Regional Centers also expressed concern that facilities may only want to accept consumers who are eligible for day programs. Since the Regional Centers fund day programs, use of day programs is one way for facilities to reduce their staffing costs. If this is the reason consumers are turned away, then Regional Centers indicated that alternate funds need to be available for facilities if consumers don't attend schools or day programs. In one case, facility staff told a CSUS research nurse that the quality of day program for some of their residents was not acceptable, yet staffing patterns precluded them keeping the residents on-site. Investigation by the CSUS nurse collaborated staff observations. DHS nurses also noted that this day program "does not meet the needs of any clients--clients are soiled, wet and not active during my observation and interviews with the RNs…" DHS noted that under W 120 483.410 (D) (3) the facility must assure that outside services meet the needs of each client. However, DHS also needs to ensure that the level of funding for facilities is adequate for them to only need to utilize the day program of school services to enhance the lives of their residents.

Regional Center staff also wondered if facilities are trying to balance consumers with behavior problems with consumers who are easier to care for. Getting the right mix of consumers is important for the safe and effective functioning of an ICF/DD-CN facility.

DHS has recently published a document, the Pre-Admission Screening Check List, to help guide facilities in evaluating consumers for acceptance into their ICF/DD-CN. This screening instrument identifies applicable federal and state regulations that define placement criterion for this level of care. Specifically, the document addresses roles of

nurses; definition of qualifying clients' health needs and developmental characteristics; required services; and CN pilot project waiver requirements. It also lists the pre-admission screening assessment requirements and the federal regulatory requirements for comprehensive functional assessments.

Two facilities currently have waiting lists, while others have vacancies. Facilities that filled their vacancies most quickly moved residents from existing ICF/DD-N facilities they owned. In one case, a facility had previously received funding to provide enhanced services for their ICF/DD-N residents; they switched over to the pilot project for enhanced funding to allow them to continue with these consumers. In another case the facility was providing care at the ICF/DD-N rate; the pilot project enabled them to draw salary for the owner's own time. This facility has an active human rights committee that helps facilitate meeting consumers' needs. For example, the neurologist serving their residents agreed to come to their facility for medical reviews to decrease the stress experienced by consumers from being transported. This agency is well-linked to the local health programs and providers, who highly recommend them to families. In addition, families are very enthusiastic about the facility and promote it to other families.

The facilities that are not operating at capacity are enrolling consumers from DCs, sub-acute facilities, and SNFs. The enrollment process is longer, since the ICF/DD-CNs are carefully trying to select consumers who will be successful in living in less restrictive environments. The Regional Centers are also working to ensure successful transition of the consumers to their new residence. This is a time consuming process. Early in the pilot project one facility was closed, primarily due to acceptance of a resident without following admission procedures and not responding appropriately to the consumer's adverse health status changes. Although the DHS' decision to close this facility was appropriate, the facility operators were well-intentioned individuals who were caught up in a series of unfortunate events. They were unskilled in dealing with the ICF/DD-CN populations' special needs. Some of those interviewed indicated that the facility owners were under intense pressure from the consumer's family, complicated by personal stressors and financial pressure due to unfilled beds. Everyone learned from this

unfortunate experience. Both DHS and the Regional Center have altered their processes to avoid similar problems. The facility operators were not able to continue with the pilot program and were unable to recoup funds expended on purchasing necessary equipment and re-modeling the residence to enable them to participate. The child involved in the incident has returned to the sub-acute facility, although his parents preferred he be placed in a less restrictive environment. Finally, the local community lost a much-needed facility. There are significant problems finding facilities willing to take children under the age of eighteen who need twenty-four hour nursing care.

Concerns were raised about the transition period from one type of environment to the next. Transition is known to be a time of increased fragility, and the Regional Centers want to know what is being done to increase stability for the consumer during this transition. It is really helpful when the facilities where consumers are living send their staff to the ICF/DD-CN to assist with the consumer's transition to the new residence.

Recommendations

Regional Centers suggest that consumers residing in facilities, such as DCs, should be accompanied by a staff member from their prior residence for the first week that the consumer is in their new environment. This would help prepare the ICF/DD-CN staff to work effectively with the consumer's special needs to promote as smooth a transition as possible. Other regional centers suggest the ICF/DD-CN staff be funded to spend a week at the consumer's residence, helping care for them, prior to their transfer. Funding needs to be available that will enable all agencies to provide this type of help during the transition from one environment to the next.

Regional Centers would like to know why consumers are being rejected. They are concerned about consumers who are both medically fragile and have behavioral disorders—these consumers are difficult to care for. Those consumers who are very medically fragile are easier, in some ways, to care for than those who have a mix of health and behavioral problems. Facilities need additional incentives to encourage them to address the extra needs of this population. In addition, clear communication regarding an appropriate case mix will help Regional Centers select consumers for referral. Joint

planning with providers, local Regional Centers, and DHS might facilitate screening and placement of consumers. In addition, this type of joint planning can aid in the development of recommendations for effective case mixes for facilities. It can also help define criterion for staffing levels when working with consumers with behavioral problems.

Department of Health Service's Assurance of Provision of Quality of Care

Early in the initiation of the pilot project some facilities admitted consumers prior to completion of the Treatment Authorization Request (TAR) process. DHS notified ICF/DD-CN facilities of the proper procedure for enrolling new residents. They also altered their process to try to make initial site visits within the first two weeks of a facility opening. ICF/DD-CN facilities are given written guidelines, "Smooth Move," that identify all preadmission, admission, transfer, and discharge requirements, including citations of the relevant federal and state regulations. The DHS nurses utilize initial visits to assist facilities in meeting federal and state regulations. One facility, for example, was advised to review Title 22 regulations and update all of their current client records using the ICF/DD-CN forms, with citation of relevant regulations (73925, 73927, and 73928). They have also advised the ICF/DD-CN of revision of their policy and procedure manual, their equipment manual, and completion of their monthly reports required by DHS. DHS routinely reviews the maintenance of equipment and resources, ICF/DD-CN's documentation of equipment maintenance and service, and makes recommendations regarding findings. DHS sites state and federal regulations to support their requirements as needed. There is clear evidence of coordination between departments within DHS, particularly between L&C and MCOD.

DHS nurses have provided increasing amounts of technical assistance to help facilities succeed. They recently provided a day-long training that included the provision of materials and documents designed to assist the ICF/DD-CN pilot projects. The following topics were addressed in the handouts:

- Nursing philosophy

- A sample health care protocol and head-to-toe assessment form
- Description of the parameters of assessing persons with developmental disabilities
- A comprehensive functional analysis form
- A nursing assessment form designed for the ICF/DD-CN pilot project
- A sample clinical record review worksheet
- A sample training/documentation audit tool
- Pain assessment fact sheet and pain assessment tool
- Infection control guidebook specific to ICF/DD-CN facilities
- A form for analysis of infection trends
- An oral health care plan
- An oral health hygiene skill survey
- Documentation guidelines
- Feeding by gastrostomy tube guidelines
- Health care plan guidelines
- Dietary guidelines for ICF/MR facilities
- Regulations for teaching consumer's money management skills

These materials were very well developed—they were clear, concise, and comprehensive. The DHS nurses selected topics for this training based on their analysis of the learning needs of the ICF/DD-CN pilot project staff. Those working with the ICF/DD-CN pilot project indicated that these materials are particularly helpful because they delineate DHS expectations of the ICF/DD-CNs. Regional Centers indicated that ICF/DD-CN facility staff need guidance on how best to develop their programs and to increase their understanding of the expectations of DHS.

DHS nurse's records demonstrate consistent attention to the quality of consumer's ongoing health care. In the case of a consumer with two chronic, serious health problems that required careful monitoring of his diet and intake, DHS staff worked with the agency to improve their care at several levels:

1. They were advised to improve overall documentation of services, including those provided by other agencies;

2. They were also advised to improve coordination between the ICF/DD-CN facility and the day program;
3. They were encouraged to revise and improve the person's plan of care;
4. DHS encouraged more client-specific staff training;
5. Conflicting and unclear medication orders were addressed by DHS.

Interviews with the Regional Center case manager supported the effectiveness of DHS's interventions. The consumer's health was significantly better than it had been in his prior residence. The case manager was also impressed with the consumer's interest in cooperating with his plan of care. The coordination between the facility and the consumer's day program impressed the Regional Center case manager.

DHS requires each ICF/DD-CN facility to submit monthly logs for the following:

- Staffing
- Admissions, discharges, and hospitalizations
- Grievances
- Clinical indicators
- Copies of special incident reports sent to the Regional Centers
- In-service training

During site visits DHS nurses compare these logs to agency records, and investigate any discrepancies. For example, during one site visit the DHS nurses noted that a health problem had not been documented in the monthly clinical log and reviewed this finding with the facility staff. The monthly logs are also used by DHS to address consumer health outcomes. Recently, for example, L&C nurses noted that when one consumer in a facility developed an infection, the remaining consumers in the facility also tended to develop infections. The ICF/DD-CN staff was observed as they provided care to residents. The L&C nurses noted that they were not washing their hands between tasks, nor between contacts with consumers. The L&C nurses brought this to the attention of the facility staff. They encouraged them to review consumers' health patterns and document analysis of findings and subsequent actions to resolve problems. This type of intervention can help facilities become more successful in managing consumers' chronic health problems.

DHS nurses monitor the quality of documentation. They assess facilities' responses to physician orders, lab values, and response to abnormal findings. When health issues were not adequately addressed, or the interventions and consumer responses were not documented, DHS staff addressed these issues with the ICF/DD-CN staff. For example, in one case a consumer had abnormal blood lab values and the physician wrote an order for them to be re-evaluated. Although facility staff, including an ancillary care provider, noted that the values were abnormal, blood lab values were not re-checked. DHS nurses pointed this out to the facility and continued to monitor for compliance. In another instance the DHS nurses noted that a facility did not enter a consumer's identified nursing needs into the care plans, nor were they incorporated into the nursing assessments. The DHS nurses recommended that the facility improve its nursing care plans to include specific nursing interventions, assessments, and actions.

DHS nurses also review the quality of documentation of care of consumers. In one case, for example, they evaluated the documentation of the consumer's health status prior to becoming critically ill. They noted that some aspects of the consumer's condition and care were either not documented or were not documented appropriately. In addition, they noted that the there was a delay in reporting the change in the consumer's status to the RN. In another instance, a consumer was supposed to be receiving services from an ancillary care provider at least 12 times a month; however, the DHS nurses noted that there was only documentation of this service one time in a 6-month period. DHS' interventions and recommendations are clearly documented in their records, along with written follow-up notification of the ICF/DD-CN facilities.

DHS oversight of the quality of care provided to consumers also includes assessment of how plans of care are implemented. Part of this analysis includes evaluation of the coordination of planning with other programs and implementation of recommendations made by ancillary care providers. In one instance, the recommendations of a recreation therapist were not being implemented and the day program was not using the adaptive feeding equipment recommended for the consumer. In another case, the plan of care required regular monitoring of a consumer's oxygen saturation level, but one of the

agencies providing off-site services to the consumer did not have the equipment to monitor oxygen saturation levels. The DHS nursing staff informs facilities of their observations during exit conferences and then follows-up within a few days of the visit with a letter describing their findings. When DHS finds serious quality-of-care problems they do an immediate follow-up site visit to monitor adherence to the plans of care. DHS visits day and school programs, where they review documents, observe care, and interview personnel regarding the quality of care and the implementation of plans of care. DHS staff ensures consumers get training in life skills, as appropriate, always citing the relevant regulations. For example, they recommend that a consumer's IPP include interventions to increase basic self care and communication skills; that they provide the client with adaptive/assistive/supportive equipment and teach the client to use them; that they allow the consumer to manage his/her financial affairs to the extent of the person's ability; and that they ensure clients the opportunity to participate in social, religious, and community group activities.

L&C has instituted a new policy: providers are required to notify them immediately when a resident is hospitalized in an acute care facility. DHS makes site visits and carefully reviews all aspects of health care when consumers are hospitalized. Attention is paid to the condition of the consumer and the quality of their care prior to their hospitalization. In one case the L&C nurses found that the consumer had received excellent care at their ICF/DD-CN facility. The new policy will ensure DHS will be able to act immediately to review a consumer's care when they are transferred to an acute care facility.

During site visits DHS nurses pay attention to consumers' safety. DHS nurses consistently review the physical environment of ICF/DD-CN facilities. They note any problems, including equipment maintenance, storage of supplies, and facility layout. In one case, latex gloves were stored in a consumer's room, even though the consumer had latex allergies. DHS staff note whether restraints, physical or chemical, are used, and whether the facility has met regulatory requirements for use of restraints. Any deviation from regulations has been addressed immediately with facilities. Any unusual marks,

including bruises or scratches, are noted and records are reviewed to ascertain causes and responses of the ICF/DD-CN staff. DHS nurses routinely advise ICF/DD-CN staff of their roles and responsibilities, citing the applicable regulations (state and federal). Follow-up letters reaffirm DHS nurses' recommendations. However, facilities with consumers who have both health and behavioral problems indicate that it is sometimes difficult to comply with regulations while ensuring protection of residents from other residents' aggressive behavior.

Regional Center personnel felt that ICF/DD-CN consumers need significantly more oversight by DHS nurses than other types of ICF facilities to ensure that residents remain as healthy as possible. The consumers have complex, multiple, overlapping chronic health problems that are significantly affected by environmental factors. The regional centers thought that the DHS reviews should focus heavily on quality of care, and should be as intense as the reviews of hospitals and sub-acute facilities. Some Regional Center staff suggested that the staff working at Agnew DC could be excellent resources for ICF/DD-CNs if it closes.

Most of the Regional Centers would like a closer working relationship with the DHS survey nurses. All would like to be notified about any deficiencies or areas of concerns. Most Regional Centers would like to know when DHS nurses (L&C & MCOD) are going to visit a facility. They would like them to communicate with the Regional Centers immediately following a site visit. If there are any major concerns, the Regional Center would like to assist the facility to change their practices in a timely manner. The Regional Center staff can also document adherence to recommended changes. Some would like to make joint assessment visits with DHS staff, including some nurses and physicians. They all expressed interest in following-up on any health care concerns, hospitalizations, and special incident reports.

Closer coordination with the Regional Centers can decrease miscommunication. In one case, DHS nurses noted that the ICF/DD-CN staff was not performing a certain procedure according to existing standards of practice, nor were they complying with their own

policy and procedure manual. The facility staff complained to the Regional Center that the DHS staff were being "picky—they can never please them," when, indeed, the incorrect performance of the procedure was probably related to adverse consumer outcomes. Had the Regional Center staff participated in the review, or if findings had been discussed with them, they could have reinforced the DHS teaching.

The Regional Centers recommend a change in the culture surrounding the DHS survey process. Currently, facility staff is anxious about site visits and spend a lot of energy trying to get charts in shape to ensure that their facility "looks good." They express disappointment and feel discouraged when they are cited for violations of regulations. Some view the DHS citations as punitive. The Regional Centers suggest that facilities be told what they are doing that is effective as well as what they need to change. ICF/DD-CN staff is very hard working and are committed to meeting the needs of those in their care. They are taking care of consumers with very complex health problems and they need positive feedback about what their work.

The Regional Centers indicated that DHS needs to provide more technical assistance to the ICF/DD-CN facilities. Providers need constructive feedback and guidance on how to do things better. The Regional Centers are interested in working with DHS to support ICF/DD-CN facilities, through quality improvement, to enable them to provide a high quality of care to consumers. The motto of one Regional Center is "Working together to make good programs better" and suggested that this should be the motto for the ICF/DD-CN pilot projects. Regional Centers also recommend that attention be paid to the quality of continuous education in homes to ensure that the education is effective and that the education address key areas, such as universal precautions and practices that influence individual consumer health outcomes.

Regional Centers requested clarification about the parameters of "twenty-four hour nursing care." If the consumers need twenty-four hour nursing care, then what happens when they want to go on an outing, go to a doctor's office, or go to day care? If they have nurses on the premises when they go to day programs or schools, does the ICF/DD-CN

ensure the availability of a nurse? Some community agencies suggest that the residents need to be more integrated into the community. However, there is some confusion about how to determine if a consumer's status is stable enough to participate in community activities. If a nurse must be present at all times the costs of additional staffing may make participation in community events prohibitive. The Regional Centers would also like clarification of what an RN can do versus what an LVN can do.

Recommendations

The DHS nurses consistently worked to review the quality of care during site visits and provide feedback to ICF/DD-CN facilities on ways to improve their services. Because of the complex nature of the consumer's health status—they have multiple, overlapping, chronic health problems that are significantly affected by environmental factors—DHS staff need to continue to routinely monitor the quality of health care. Regional Center staff indicated that this is a key component to ensuring the safety of the consumers residing in ICF/DD-CN facilities. The Regional Centers suggest quarterly visits that focus extensively on health care. The more comprehensive site surveys, where compliance with all regulations is addressed, are not needed as frequently.

DHS staff has provided increasing levels of technical assistance to facilities. This is a commendable activity. They need to incorporate these activities into a general quality improvement program. DHS should coordinate this work with local Regional Centers. Consideration should be given to joint planning with each facility and each Regional Center, mutually establishing goals for improving the quality of care and developing plans to support achievement of desired outcomes. Each Regional Center has unique staffing patterns and policies, so relationships with DHS and Regional Centers need to be negotiated locally. This would also enable DHS to answer Regional Center questions, such as those about the roles of RNs versus LVNs. Although the facilities would prefer quarterly rather than monthly reports, monthly reports are recommended. These reports offer a simple way of monitoring trends and patterns of consumers' status in the ICF/DD-CN facilities. One suggestion is that the DHS nurses currently working with the ICF/DD-CN pilot project could focus their visits on quality improvement. The annual surveys,

then, could be done by the regional L&C offices. Finally, it is essential that DHS nursing staff levels are adequate to provide the level of technical assistance needed to ensure the safety of the consumers and the success of the pilot projects.

DHS' Ability to Evaluate Consumers' and Providers' Satisfaction

Consumers

DHS documents the results of interviews with consumers or their guardians for each facility. There has been a high degree of satisfaction with the ICF/DD-CN pilot project. Interviews with family members support DHS findings. As one mother indicated, "I feel my child is safer now because of the twenty-four hour care with nurses. She has a lot of medical problems and I feel she is in good care…The home is a nice environment and not stuffy and cold like hospitals…The staff is caring and she was able to transfer with another girl she has lived with for the past year." Comments of all of those interviewed were consistently positive.

The Regional Centers describe the ICF/DD-CN staff as knowledgeable of how to deal with their clients. One consumer, for example, has survived much longer than anyone expected. The staff at the ICF/DD-CN took the time to explain his health needs to him, and he is now cooperating with his care. Since moving to the ICF/DD-CN he is cooperative with his care and much happier. Another client was in a sub-acute, where she spent the bulk of her time watching TV. She was withdrawn and had poor peer relationships. Since moving into the ICF/DD-CN she has gone to the zoo, gone shopping, and is forming enjoyable peer relationships.

Higher functioning residents were very proud of where they lived, and happily showed research nurses around their "home." They seem delighted with the opportunities they have enjoyed since moving to the ICF/DD-CN. Consumers are surprised that staff is giving them options. The staff is very caring and the consumers are happy with their placements. However, they also expressed anxiety about losing their homes if the ICF/DD-CN pilot project is ended. These concerns were echoed by Regional Center staff. They worried that consumers who are hospitalized for any length of time may not be able

to return to their "home" because an ICF/DD-CN facility can't hold an unpaid bed indefinitely. The Regional Center personnel felt that those who reside in ICF/DD-CN facilities experience significantly more individual freedom and a higher degree of emotional intimacy with staff than they would in larger institutions. They worry about the trauma consumers would experience if they had to leave such a personal, close environment and return to the more impersonal environments of larger institutions.

DHS' has clearly defined complaint and grievance protocols. DHS reviews addressed placements of consumer's rights and the complaint/grievance process in visible and easily accessible locations. Documented evidence indicates that these protocols are followed. In one case a parent complained that their child was sustained an injury while being transferred form the facility to the day program. DHS investigated the compliant, noting that the injury was caused by an equipment failure. Problems with this equipment had been noted previously, but the day program had not repaired it. DHS fully investigated the incident, and notified the facility of the deficiencies, citing the appropriate regulations regarding contracts with and expectations of services from other agencies. Only one grievance was filed during the first six months of the ICF/DD-CN pilot project. A consumer was unhappy with the way a staff person interacted with him. The facility reported the grievance and resolution to DHS. In follow-up DHS discovered that the facility eventually decided to terminate the employee since they did not have the type of attitude they wanted from persons who work with their residents.

Providers

The providers seem to be very attached to their residents and are concerned about meeting their needs. Several facilities have garnered extensive support from their local communities. One facility, for example, received donations to build the ICF/DD-CN facility from members of their local community. Another facility has a very active Human Rights Board whose members advocate for additional services for the residents.

Providers have expressed two general concerns. First, the providers who aren't at capacity are worried about their ability to stay in business. One facility decided to drop

out of ICF/DD-CN pilot project because the expenses and future costs were more than they could absorb. Another area of concern is the review process. As noted in a survey reported by DHS, the providers want DHS to, "Educate us to do it right, don't tear us down." As discussed previously, providers desire more positive feedback from DHS nurses, both verbally and in written evaluations. They would also like assistance in improving their functioning.

DHS surveyed providers about their experiences with the ICF/DD-CN pilot project. Five areas were addressed:

- What they wanted from Regional Centers for help in getting clients
- What they want from Regional Centers for support
- Were Regional Centers helpful in pre-admission visits
- What type of support were they looking for from DHS
- Any suggestions

Providers indicated different experiences with Regional Centers. Two facilities filled their beds by transferring eligible consumers from other locations they owned, thus having minimal Regional Center involvement. Regional Center involvement with the other facilities ranged from none to increasing activity. The pilot projects wanted more assistance from Regional Centers in completion of forms, and more help with managing medically fragile consumers, coordinating with day or school programs, and working with families. Surveyed facilities wanted assistance from DHS to facilitate paperwork for admissions, to establish a support network, and to increase support and positive feedback. They also suggested improvements in how to market the ICF/DD-CN pilot projects, improve referral sources, and the need to increase positive attitudes toward the pilot facilities. The findings of the DHS survey were consistent with the research team's findings from interviews with the facilities and the regional centers. The major focus of concerns of the ICF/DD-CN facilities was filling un-filled openings and their need for more positive feedback about their work.

Regional Centers

Regional Center staff expressed a high degree of satisfaction with the existing ICF/DD-CN pilot projects. They indicated that consumers are treated very well, that families are happy with the services, and that the staff are highly skilled and emotionally sensitive to the residents. The ICF/DD-CN personnel know the consumers very well and immediately pick up subtle cues of discomfort and health status changes. The Regional Centers were also impressed with the physical layouts of some facilities. They indicated that the physical plant is important and should be built based on the needs of the consumers and allow easy access of staff and equipment in case of an emergency. One facility, for example, was built for this project, with the construction and design created to accommodate the needs of people with developmental disabilities. The physical set-up allows for the availability of technological support at the bedside, yet the facility is a home and each resident has his or her own room.

Recommendations

There is a high degree of satisfaction with the quality of life for residents living in ICF/DD-CN facilities. Positive feedback was received from consumers, their families, and Regional Center staff. Providers are very committed to their residents. Unfilled beds are a serious problem for the ICF/DD-CN program. DHS, as stated previously, needs to establish closer coordination with local Regional Centers. Joint planning meetings with individual Regional Centers to discuss ICF/DD-CNs' needs, including the need for consumer referrals, should be established on a regular basis. Each Regional Center has unique staffing patterns and policies, so relationships with DHS and Regional Centers need to be negotiated locally. Finally, as mentioned previously, consideration should be given to changing the culture of DHS sight visits. ICF/DD-CN facilities have consistently indicated the need to hear more about "what they do right." Obviously, problems need to be addressed. However, it is also recommended that their strengths be identified since this reinforces the positive strides they are making in provision of care for this fragile population.

DHS Educational Outreach

DHS provided outreach to ICF/MR facilities, Regional Centers, Developmental Centers, and community groups to promote the ICF/DD-CN facilities. DHS used a number of

methods to promote the ICF/DD-CN Pilot Project. In the newsletter "BROAD-CAST NEWS…" produced and distributed by the Developmental Services-Consultation and Support Team (CAST), (formerly called the ICF/MR Newsletter) provided ongoing information about the pilot project from the time it was initially proposed. A series of articles described the pilot project and conditions of participation. DHS prepared a series of brochures for consumers and their representatives, Regional Centers, potential providers, and physicians. DHS provided a series of educational programs for Regional Centers to encourage them to identify consumers who might benefit from residing in an ICF/DD-CN pilot facility. They also visited Developmental Centers to promote the pilot project.

Delays in enrollment were more strongly related to concerns about the long-term viability of the ICF/DD-CN pilot project than lack of advertisement and promotions. The ICF/DD-CN facilities that were able to enroll consumers in a timely manner were those that identified people already residing in their other facilities. One provider had been providing twenty-four hour nursing care for several years with enhanced funding from their local Regional Center. These consumers met eligibility requirements and were easily transferred into the pilot project. It was easier for providers with existing links in the local community, excellent reputations, and strong existing ties to their local Regional Center to secure referrals and enroll consumers. To some extent, some of the most effective promotion of the pilot projects was done locally. In larger communities, facilities were more dependent on referrals from Regional Centers, SNFs, DCs, and sub-acute facilities. Regional Center staff has had to try and convince families to give up their current placements. Many have refused because the ICF/DD-CN is a "pilot project", and, therefore, possibly a temporary type of placement. This combined with the fear that medically fragile family members will not survive in ICF/DD-CN facilities, has created barriers to placement—some families have heard horror stories about community care. As Regional Centers have become more confident of the longevity of the ICF/DD-CN pilot project they have increased their support of the DHS outreach efforts. Regional Center staff, including physicians and nurses, visited some facilities. Regional Centers

also invited some DC staff to visit ICF/DD-CNs to encourage them to support placement of eligible consumers.

The Regional Center staff, impressed by consumers' positive responses to ICF/DD-CN facilities, indicated that media documenting consumers' happiness and comfort in the home-like setting of an ICF/DD-CN would help them promote placements in pilot project facilities. This would be particularly helpful in encouraging parents to consider ICF/DD-CNs as a viable alternative placement for their children. Media that documents the enthusiasm of consumers, their families, and Regional Center staff could increase support and reduce resistance to consumers residing in these less restrictive environments.

The two facilities that are operating at capacity have waiting lists of consumers hoping to have the opportunity to reside there. The requests are based on their reputations within their local community. Basic word-of-mouth seems to be the best form of advertisement for the pilot projects—if the facilities demonstrate their ability to perform well then families support placements in ICF/DD-CNs. A key focus of this project must be to ensure a high quality of care. Consumers, parents, and regional center personnel all praise the warmth, caring and home-like atmospheres of the ICF/DD-CN facilities. The key area of concern is ensuring that the health care is safe and comprehensive. The consumers have complex health problems requiring careful management. DHS needs to provide enough support and oversight to ensure the ICF/DD-CN facilities continue to develop the expertise needed to manage consumer's needs in less restrictive environments.

Recommendations

The great strength of the ICF/DD-CN facilities is the provision of a warm, home-like atmosphere that supports individual growth. Media showing individuals thriving in this new type of environment can support the value of ICF/DD-CN facilities. This type of media could be particularly helpful to family members who have concerns about the value of this type of residential facility. In addition, DHS's enhanced oversight of this program provides increased assurance that consumers' health care needs are being met. The quality of ongoing health care is viewed by Regional Center employees as a crucial factor in the success and acceptance of ICF/DD-CN facilities. Since DHS is providing

more oversight than they traditionally provide, media needs to document this enhanced oversight. In addition, media should provide documentation of the materials produced by DHS to support these facilities.

Cost Effectiveness of the ICF/DD-CN Pilot Program

DHS submitted a table, the ICF-DD-CN Waiver Cost Effectiveness Analysis, displaying the method of cost effectiveness analysis they planned to use for the ICF/DD-CN Waiver (see page 34 of 36). As can be seen on Table 1, the pilot project is not cost effective at this time. A number of factors have influenced this outcome. First, the two pilot projects that are filled to capacity enrolled most of their residents from ICF/DD-N facilities. In their waiver application DHS projected that ICF/DD-N facilities would be the source of 15% of the referrals for the ICF/DD-CNs. Currently, however, 54% of the ICF/DD-CN consumers formerly resided in ICF/DD-N facilities. It is important to note that the care of consumers in one ICF/DD-N facility had been significantly supplemented by the local Regional Center. In fact, the Regional Center considered this facility a "pilot program" that tested the ICF/DD-CN model for several years. Also, the costs listed for DCs do not include overhead expenses; the current average daily cost per DC resident is $559.00.

Table 2: ICF/DD-CN Waiver Cost Effectiveness Analysis

Facility	Number of Clients	ICFDD-N	Sub-Acute Adult	DC	Acute Care	Vent	Non-Vent	Cost 1	Cost 2	Net Waiver Costs
1	6	5			1	5	1	$2,707.85	$2,294.53	$413.32
2*	6	6					6	$1,089.42	$2,142.18	$1,052.76
3	4		2	2		2	2	$1,509.90	$1,489.06	($20.84)
4	3	2	1			1	2	$903.26	$1,101.56	$198.30
5	4	3	1			2	2	$1,084.83	$1,489.06	$404.23
6	2			2			2	$729.72	$714.06	($15.66)
7	0									
Total	25	16	4	4	1	10	15	$8,024.98	$9,230.45	$2,032.11

Note: Cost 1 = daily cost in previous residence
Cost 2 = daily cost in current residence

* Funding for this facility was augmented beyond the ICF/DD-N level by the Regional Center to cover the cost of twenty-four hour nursing care.

Also, the enrollment in the ICF/DD-CN pilot project has been delayed. There are too few consumers in the pilot project to allow any valid evaluation of the cost benefit of this

project. There needs to be more data on more consumers over a longer time period to adequately evaluate the cost effectiveness of the ICF/DD-CN pilot project.

Regional Centers and facility operators point out that it is important to consider the current financial pressures experienced by the facilities with unfilled beds. One facility had two consumers, one who died while in an acute care hospital (the quality of residential care was not a factor in this person's death), and another who was hospitalized in acute care and is now in rehabilitation. Another facility decided to end their participation in the ICF/DD-CN pilot project because costs of care were too prohibitive for them to continue. Two residents were residing in this facility at the time of their decision. Some facilities received financial support from their local Regional Centers to help with expenses related to the physical modification of their facility. One facility was able to raise enough financial support in their community to build a brand new, state-of-the-art building. Some facility operators used their personal funds to make expensive and extensive changes in their facilities and to purchase special equipment, thus placing themselves at financial risk. This risk was further increased when beds remained unfilled. A large 150-bed facility can survive with a few unfilled beds, as can state-run facilities, but small, privately operated facilities may not be able to financially tolerate either lack of placements of the loss of placements if consumers are hospitalized. They cannot operate fully staffed if 1/6 of their income, for example, is lost if a resident is placed in an acute care hospital for any length of time.

Other fiscal factors have also adversely affected the ICF/DD-CN pilot projects. Regional Centers pointed out that some excellent facility operators opted to not apply for the ICF/DD-CN pilot project because of the lack of start-up funds. In previous pilot projects, such as when the ICF/DD-N facility model was tested, Regional Centers indicated that they were funded to provide start-up money, on a competitive basis, for facilities interested in participating during the pilot period. The lack of start-up funds for the ICF/DD-CN pilot project decreased the applicant pool, and significantly financially stressed some of the pilot project facilities.

The Regional Centers also pointed out that ICF/DD-CNs are expected to have potential consumers spend time at their facilities, including overnight stays, prior to them being placed in the facility. This is particularly true for those being placed from DCs. In some cases, consumers visit numerous times, from four to six short-term stays, before placement. The Regional Center staff expressed concern that facilities must assume all costs related to these visits, including the expense of twenty-four hour nursing care. However, Regional Centers also stated that it is important that the placement process not be rushed. Because this is a pilot project, facilities and agencies involved in placing consumers, have a learning curve about how to select the best candidates for placement in ICF/DD-CN facilities. Regional Centers indicated that it is also important to support the facility and the consumers during the transition period. Start-up funds could provide fiscal support for the pilot projects while all of those agencies involved in the ICF/DD-CN pilot project increase their expertise in the selection and placement process. The pilot project facilities are assuming the total financial risk under the current process**.**

The ICF/DD-CN facilities have been adversely affected by community economic changes. Nursing salaries, for example, are now $45.00 per hour in some areas; they may go higher if the nursing shortage continues. Some regions, such as the Bay Area, are higher cost areas, yet funding is the same for all ICF/DD-CN pilot projects. The Regional Centers indicated that state funding must be responsive to these changes.

Finally, regional center staff pointed out that there is a lack of placements available for individuals who are under the age of eighteen who need twenty-four hour nursing care. Currently, the vast majority of SNFs will not accept consumers under the age of eighteen. In addition, the DCs are not accepting new residents. This leaves no where for individuals to reside, unless they meet criteria for placement in a sub-acute residence. The ICF/DD-CN pilot projects offer a needed service.

Recommendations

The ICF/DD-CN pilot project has encountered some unanticipated barriers, all related to the downturn in the California economy. The decrease in the state budget resulted in delays in extending the pilot project, which adversely affected placement of consumers in

ICF/DD-CN facilities. Unfilled beds strained facilities financially, and resulted in the withdrawal of one facility from the pilot project. This problem is compounded by the reduction of state staff, particularly the nursing staff who provide oversight of consumers' welfare and also provide needed technical support to the pilot projects.

Consumers currently residing in pilot project facilities and their families are very pleased with this option for twenty-four hour care. Those providing the care are dedicated to their residents and to the success of this needed service. Although this is a time of financial stress for California it is important to not lose perspective about the value of the ICF/DD-CN pilot project. If the ICF/DD-CN pilot projects are successful, the long-term savings can be extensive. In addition, they will provide a valuable alternative for consumers and their families. This project needs more time to stabilize. In the meantime, consideration should be given to suggestions from the Regional Centers that "stop gap" funding be available for the following:

- To assist facilities while waiting for all beds to be filled
- To enable facilities to hold beds for residents who are hospitalized for more than seven days.

Regional Centers indicated that buildings built to accommodate the special needs of the population served in the ICFDD-CN Pilot Project provide the best physical environment for consumers. Hallways, rooms, bathrooms, and so forth that are built to be accessible to consumers in beds and adaptive wheel chairs are far superior to houses that are altered to meet consumer's needs. In addition, specially designed homes offer better accessibility to emergency services. Start-up funds are needed to assist facilities to remodel or build the ICF/DD-CNs to ensure that they are modified to meet the needs of those they serve. This will also avoid putting facility operator in financial risk during the initial period of operation.

Regional Center staff pointed out that there are ongoing efforts to sponsor bills that will close down DCs, and they anticipate this will continue. Of particular concern is the proposed closure of Agnews DC; this will increase the number of persons needing special

residences. Some Regional Centers suggested that California consider incorporating aspects of the Oregon ICF/DD-CN model to ensure the success of this program. Oregon closed DCs and developed six-bed facilities that were built to meet the needs of those with developmental disabilities. Many are state owned and operated, while others are state owned and privately operated. This type of arrangement ensures that the facilities will have longevity. The recent closure of one ICF/DD-CN pilot facility due to financial pressure was very hard on consumers and will increase family resistance to placement. Of particular concern is the impact this type of closure may have on consumers who have thought of a residence as their home and who have developed a comfort in living in a more intimate and less restrictive environment. How will they adjust if they have to go live in a SNF, where many of the other residents are old, and staff is less stable? Some Regional Centers suggest that California adopt Oregon's policy of state-built, privately operated facilities, and state-built and state-operated facilities. This would decrease financial burdens for providers as well as increase the potential for stability and longevity of residences for this population.

Conclusions

DHS staff has endeavored to establish an effective ICF/DD-CN pilot project. There is evidence of excellent collaboration among state agencies, including within DHS and between DHS and DDS. DHS nursing staff working in MCOD and L&C has provided extensive oversight for this program. They are very knowledgeable of Federal and State regulations and ensure that ICF/DD-CN facilities operate in compliance with these regulations. They follow-up on all recommendations and ensure that they are implemented. They monitor and analyze monthly reports and investigate all hospitalizations. The DHS nurses have developed written materials to provide technical support for the ICF/DD-CN facilities.

It is recommended that DHS develop more collaborative relationships at the local level, particularly with local Regional Centers. A closer link with the local Regional Centers is particularly important for the following activities:

- Selection of new facilities: Regional Centers' local insight can augment DHS evaluations of facilities;

- Oversight of quality of care: Regional Centers can follow-up on DHS concerns, reinforce recommended changes, and help monitor consumer health;
- Provision of technical assistance: Regional Centers could augment and support DHS technical assistance, as well as report changes in practices within ICF/DD-CNs as a result of technical assistance;
- Placement of residents in facilities: Regional Centers can work with DHS to identify appropriate consumers and help identify appropriate case mixes;

Limited funding for some aspects of the ICF/DD-CN program has created some hardships, in particular the lack of start-up funds. In addition, consideration should be given to providing stop-gap funding while agencies are beginning to fill beds, and when residents are hospitalized for extended periods. As more is learned about the characteristics of consumers best suited for ICF/DD-CN facilities, and as more is learned about appropriate case mixes, there should be less of a need for stop-gap funding.

Consumers, their guardians, and their Regional Center case managers have all expressed great enthusiasm for the ICF/DD-CN facilities. They provide a needed level of care in local, home-like environments that has not previously been available. This program needs more time to stabilize, and will need ongoing enhanced support from DHS. It is particularly important that the level of nursing oversight be maintained for this medically fragile population. Facility staff, including their licensed nursing staff, has needed the expertise of the MCOD and L&C nurses to assist them in improving their skill in managing the complex needs of the consumers for whom they care. The ICF/DD-CN nurses will need to become clinical experts in the management of individuals with developmental disabilities who are medically fragile. Although the nurses may have expertise in caring for specific problems, the art of caring for individuals with complex, interwoven problems within a home-like environment will, in many cases, require a learning curve. The expertise of the DHS nurses is important for supporting this change.

The greatest value of the ICF/DD-CN facilities is the opportunity for consumers to have warm, intimate, personal relationships with a consistent group of caregivers. ICF/DD-

CN facilities support individuality and the opportunity for personal growth. They also enhance consumer's ability to maintain closer ties with their local community. The greatest risk to consumers is inadequate management of their health. With adequate support, oversight and technical assistance ICF/DD-CN facilities should be able to provide health care as effectively as they provide emotional support.